National SDS Collaboration

Connected Conversations

Learning Report from Outcome 3 Conversations

2025

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in Control Scotland

INTRODUCTION AND SCOPE

Conversations with disabled adults and unpaid carers have told us that they feel their thoughts and feelings are not adequately represented in national SDS discussions.

We know many feel frustrated and disillusioned by ongoing consultations that lack meaningful outcomes or change.

Disabled adults and unpaid carers want to be heard, but they also seek a safe and flexible space for participation.

We are optimistic that this newly designed model will help close the feedback loop more effectively, aiming to build trust and confidence among disabled individuals and unpaid carers, leading to meaningful change.

This is a report from engagement with 56 disabled adults and unpaid carers giving their thoughts and feelings in relation to 5 questions asked about Outcome 3 of the National SDS Improvement Plan.

Outcome 3 Questions:

These questions are about being part of the process to decide how you get support:

3.1 Have you ever been involved, or been invited to be involved, in local planning for social care?

3.2 Are you able to use your budget flexibly?

3.3 Were you told the value of your budget?

3.4 Do you have a carers' budget? If so, what has been your experience?

3.5 What do you think needs to change / what would it take to close the gap between your experience and living a good life?

APPROACH

From June to September 2025, 56 participants responded through a range of methods:

- We received over 31 completed easy-read questionnaire results using a Microsoft Teams form
- 2 group discussions with a combined total of 17 people facilitated by GCIL and the SDS forum in the Borders
- 8 individual face-to-face conversations facilitated by In Control Scotland

Findings will be presented at the National SDS Collaboration meeting on 1st October 2025.

Feedback and any relevant action points from the National SDS Collaboration will then be shared with everyone who has asked to be kept updated of progress, as well as a copy of this report.

OUR LEARNING

All responses have been gathered and summarised into key themes.

Some people shared detailed thoughts; others gave brief agree/disagree or yes/no responses. We're grateful to everyone who took part.

Findings, responses, and any actions will be shared with those who have requested feedback.

These conversations have generated a wealth of rich, often raw, data. For clarity, we've grouped the insights into key themes, which will be shared in the report.

An easy-read report is also available.

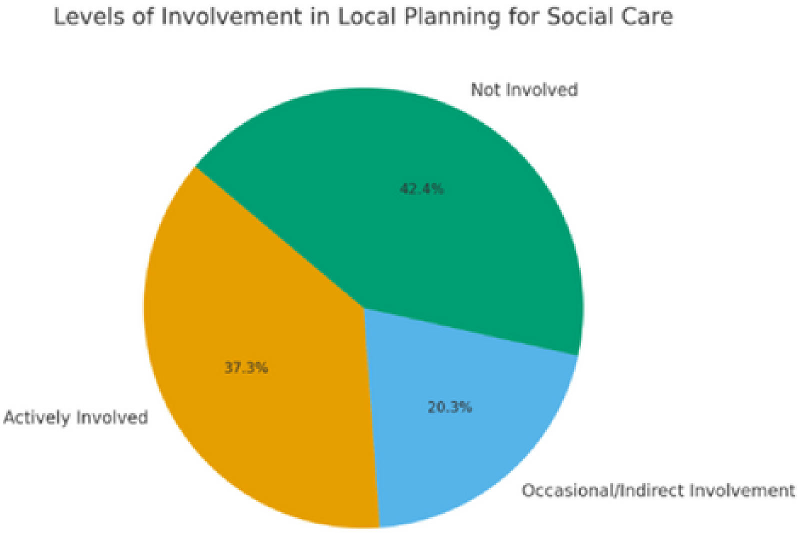
QUESTION 1

3.1 Have you ever been involved, or been invited to be involved, in local planning for social care?

The rich and detailed feedback we received for this question demonstrates that while there are positive examples of meaningful engagement, where lived and loved experience has shaped SDS development, training, and service design, such experiences are the exception rather than the norm. Many participants described tokenistic consultation, inaccessible systems, undervaluing of expertise, and disconnection between national commitments and local delivery.

Where engagement was done well it empowered participants, improved services, and built confidence and networks. However, when involvement was poorly supported or superficial, it left people disillusioned and excluded. The overall picture shows that Scotland's systems are not consistently realising the SDS principles of choice, control, and co-production.

Statistical Breakdown in response to Q1:



From the responses received here is a visual summary showing the approximate levels of involvement in local planning for social care:

- 37% actively involved
- 20% occasional or indirect involvement
- 42% not involved at all.

QUESTION 1
(CONTINUED)

We have gathered the feedback received from online questionnaires and face-to-face conversations that took place and collated it into key themes for learning and reflection.

Key themes identified:

Theme 1: Positive Engagement and Impact

Some participants gave strong examples of meaningful involvement that shaped decisions and improved services. Test sites for SDS, contributions to social worker training, and participation in boards or strategy groups gave disabled people and carers a sense of real influence and recognition of expertise. Engagement in initiatives and programmes such as Partners in Policymaking, Working Together for Change, IMPACT, GCIL, SDS Forum Borders, and Glasgow Disability Alliance's Expert Group empowered individuals, building skills, confidence, and networks. What we heard included:

- **Impact:** Early involvement in the SDS test sites directly influenced processes still in place today.
- **Capacity Building:** Training, advocacy groups, and voluntary board membership gave participants not just a voice but long-term skills and leadership opportunities.
- **Networking and Confidence:** Engagement often led to further opportunities, expanding people's capacity to influence policy and practice.

"Partners in policymaking and WTFC gave me knowledge, skills, and experience to help me be more confident in local planning. If I didn't get involved in these events, then my life could be really, really different."

"I have a vested interest in being part of these decisions and discussions because they affect me and my life."

QUESTION 1
(CONTINUED)

These examples show that when engagement is authentic and supported, it delivers benefits both for individuals (empowerment, advocacy skills, self-confidence) and for services (better-informed policy, stronger co-production).

Theme 2: Tokenism and Lack of Follow-Through

Despite some positive experiences, many respondents described engagement as superficial. Involvement often felt like a “tick-box” exercise: people gave time and energy but saw no outcomes, no follow-up, and no explanation of how feedback was used. Participants told us:

- **Perceived Ineffectiveness:** Feedback was often “filed away” rather than acted upon.
- **Wasted Effort:** Participants felt disillusioned when their contributions led nowhere, even after significant personal investment (e.g., travelling long distances).
- **Loss of Trust:** Over time, people stopped offering ideas or participating because decisions seemed pre-determined.

“There was no clarity on how my input was used, no timelines provided, and it felt more like a ‘tick-box’ exercise.”

“In my area... planning or review is always on their terms, never collaborative as the process and direction has already been decided.”

“I asked someone in the HSCP what they did with all the feedback from people with lived experience. He said it all just goes in a file somewhere. In other words, they’re not really taking any notice.”

Tokenism damages trust. Instead of empowering people, it reinforces perceptions that their expertise is undervalued and their time wasted. This undermines the spirit of SDS, which is meant to ensure genuine partnership.

Theme 3: Barriers to Inclusive Participation

Practical and systemic barriers — such as timing, accessibility, rurality, and lack of support — frequently excluded people from meaningful involvement. What we heard:

QUESTION 1

(CONTINUED)

- **Accessibility and Support Needs**: Without proper support, people felt unsafe or unable to participate fully.
- **Inflexible Scheduling:** Meetings at unsuitable times excluded carers balancing work, school, or caring responsibilities.
- **Geography:** People in rural communities felt forgotten and excluded, as most opportunities were urban or centralised.
- **Transitions:** Opportunities diminished during transitions into adulthood, with families and individuals losing points of contact that they had whilst their child was in education.

"It's important people think about what it takes for people like me to be involved… they need to make sure the right support is available so I can share and be safe in what I share."

"Meetings are inflexible and at times not suited to carers of people who work, attend school or day services, i.e., times at 2–4 etc."

"Living in a remote village limited access to opportunities compared to more central locations."

Unless participation is deliberately designed to be inclusive, it risks reinforcing existing inequalities. Without flexibility and investment in support, the voices of disabled people and carers are systematically filtered out.

Theme 4: Lived Experience is Valuable but Undervalued

Participants repeatedly emphasised the importance of lived experience in shaping social care. Yet many described frustrations that their insights were dismissed, ignored, or treated as secondary to professional expertise.

- **Devaluing Expertise:** Despite lived experience being central to SDS, people felt professionals often failed to see them as "experts" in their own lives.
- **Missed Opportunities**: Systems rarely sought lived experience proactively, relying instead on individuals to push for involvement.
- **Desire for Early Involvement:** People wanted to shape services from the start, not just when decisions were nearly finalised.

"Sometimes it feels like my lived experience isn't valued by the people making decisions."

QUESTION 1
(CONTINUED)

“I would really appreciate being asked for my views, as I have ideas about what would make services better for people like me.”

“It’s important that disabled people like me are part of these discussions… so we can think of ways to improve things.”

The undervaluing of lived experience undermines SDS principles of choice and control. Conversely, when lived experience is treated as expertise, it brings insight, innovation, and realism to planning.

Theme 5: Disconnection and Missed Opportunities

Respondents highlighted a gap between national policy commitments and local delivery. While national rhetoric emphasises co-production and collaboration, people at local level often felt excluded or only involved when convenient for authorities.

- **National vs Local Divide:** People noted that while co-production is promoted nationally, local authorities often restrict engagement to narrow consultations.
- **Lost Connections:** Some individuals who were involved earlier in their journey reported falling off the radar during adulthood or later life.
- **Third-Sector Variability:** In some cases, engagement depended entirely on whether local third-sector organisations created opportunities.

“I have been in touch a few times to make suggestions and you stop offering after a while. I feel a door is always closed because it doesn't tick a box for them. As a parent carer I don't feel my local authority do true collaboration well.”

“The local authority has not involved me in planning, either personally or professionally. Despite having relevant experience… they have not recognised the value I could bring.”

“None of the promised collaboration happened — in fact, there was no conversation with me at all. When I raised concerns, I was passed between five different social workers, and my complaints were never upheld. So to answer simply: I haven’t been invited into any planning, not even the planning that directly affected my child”

QUESTION 1
(CONTINUED)

“In my area... it feels like planning or review is always on their terms, never collaborative.”

This disconnection wastes opportunities to embed co-production and leads to inconsistency across Scotland. People with lived experience recognise the gap and lose trust in planning systems that fail to deliver on national promises.

Concluding thoughts

The Self-Directed Support (Scotland) Act 2013 established the right of people to have choice, control, and collaboration in decisions about their social care and support. It enshrines the principle that support should be planned ***with*** people, not ***for*** them.

The findings show that Scotland has pockets of strong practice where SDS principles are realised, but these remain uneven and fragile. To fully meet the intentions of SDS legislation and guidance, involvement in social care planning must:

- Move from sporadic consultation to sustained co-production,
- Invest in accessibility and support for participation,
- Treat lived experience as equal to professional expertise, and
- Ensure transparent follow-up so that contributions lead to tangible change.

When these conditions are met, disabled people and carers are not only partners in planning but also catalysts for innovation, inclusion, and better social care outcomes, realising the vision of SDS as a rights-based, person-led system where services are shaped with people, not simply for them.

QUESTION 2

3.2 Are you able to use your budget flexibly?

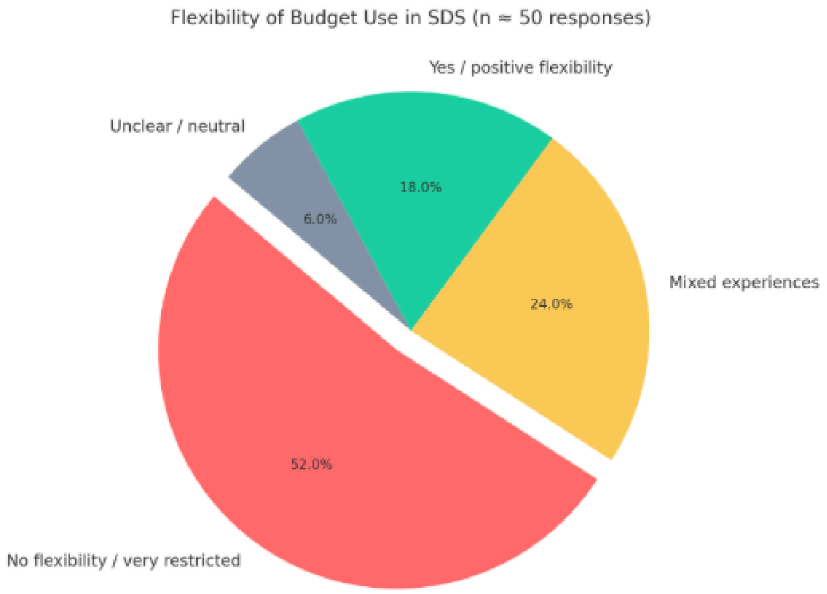
The feedback we received from participants on budget flexibility within Self-Directed Support highlights significant disparities in how the principles of choice and control are applied across Scotland. Feedback highlighted:

- Positive experiences show that flexibility can transform lives, fostering independence, participation, and wellbeing.
- Flexibility is inconsistent, with outcomes shaped by individual workers, local authority interpretations, or people's ability to challenge decisions, resulting in inequality across communities.
- Most experiences, however, reveal restrictions: budgets confined to traditional care models, blocked access, bureaucratic hurdles, and clawbacks of unused funds.
- Systemic barriers such as approval processes, inconsistent guidance, and funding cuts are undermining the original intentions of SDS.
- Children's services often allow more flexibility than adult services, but this drops off at transition points, leaving families feeling unsupported.

The evidence demonstrates that while SDS principles exist in law and policy, practice often falls short, leaving people without the flexibility needed to live independent, self-directed lives.

QUESTION 2
(CONTINUED)

Statistical Breakdown in response to Q2:



Out of 50 responses:

- No flexibility/very restricted (52%)
- Mixed experiences (24%)
- Yes/positive flexibility (18%)
- Unclear/neutral (6%)

We have gathered the feedback received from online questionnaires and face-to-face conversations that took place and collated it into key themes for learning and reflection.

Key themes identified:

Theme 1: Positive Experiences of Choice and Control

Where flexibility was enabled and supported, people described life-changing transformation and improvements in their life with increased independence and genuine choice: being able to study, pursue activities, and live independently, being some examples that were shared.

These stories illustrate the full potential of SDS when applied as intended, showing that trust, collaboration, and creativity between social workers and people can deliver powerful, transformative, and meaningful change.

"I went from having no control over my support to full control, and this made me realise how much I had lost and how unhappy I was and had become."

"When my son first started receiving SDS there was a very proactive Social Worker… She helped make very flexible choices in using my son's budget."

QUESTION 2
(CONTINUED)

"Social work wanted me to just use my budget for personal care, but I wanted to use it to help me go to College, and we made this happen."

"Now I feel really supported, and my voice is really central to everything, so I can get on with my life. Now I'm always at the centre of decision-making processes."

Theme 2: Inconsistency and Inequality

Experiences of flexibility varied dramatically and is clearly not guaranteed; it depends on location, local authority practice, the interpretation of guidance, or the willingness of individuals to challenge decisions. This undermines the principle of fairness and equality at the heart of SDS, as access to flexibility should not depend on geography or personal persistence.

"At first, when I had a brilliant social work assistant who was creative and positive, she encouraged flexibility — like suggesting a Rangers season ticket. But since she left, I've had mixed messages about what is allowed."

"There is Direct Payment Guidance which encourages flexibility, but the reality is that it is not always easy to use a budget flexibly. Most people now only have critical personal care. There is inconsistency across teams."

"Yes, but only because I represented myself in a Judicial Review against my local authority. Prior to that, no, I had no choice or control at all over how it was spent."

"I constantly need to check and challenge things, and the answers aren't consistent."

Theme 3: Restricted to Traditional Models of Care

Many people reported their budgets being limited to personal care or payroll, with little room for creativity, even when alternative supports would better meet outcomes.

QUESTION 2
(CONTINUED)

Limiting budgets to staff payroll or personal care reproduces traditional service-led models, contrary to SDS aims of enabling creative, outcome-focused support.

People reported being denied tools, activities, or resources that would clearly contribute to independence and wellbeing. This reveals a systemic drift back toward service control, away from individual choice and control.

"What flexibility? … It was made very clear to me that my budget is only for paying support staff. There is no flexibility."

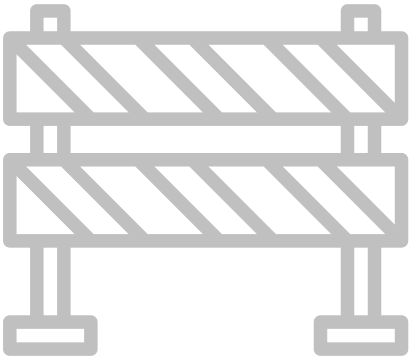
"No, we cannot get qualified carers so asked to use it for cleaner, swimming pool access, zoo visits… the answer was always no."

"We have been given the option of SDS, but Social Work felt option 3 would be the best, and we went with their suggestion. I think we can access short-term respite, but anytime I have tried to access it for my mother, I'm told it's not available."

Theme 4: Barriers Created by Processes and Bureaucracy

A theme we have heard before in outcomes 1 and 2 of the connected conversations series focuses on barriers created by process and bureaucracy.

Approval processes, inconsistent messaging, payment structures, delays, and clawbacks of unused funds prevented budgets from being used responsively, denying them the ability to use their budget in real time, which then affects independence, confidence, and can impact outcomes.



QUESTION 2
(CONTINUED)

This bureaucracy undermines the principle of participation and dignity, as people are treated as managers of paperwork who are constrained by local authority systems and procedures rather than autonomous individuals shaping their own support.

“The greatest inflexibility which still exists is the need for approval which can slow down or miss the need.”

“It’s a fight to pay for things.”

“The system doesn’t allow me to respond to real-life situations, even though that’s what SDS is supposed to enable. I was even required to return a significant amount of unused budget (£10,000) despite needing support. The lack of flexibility is affecting my well-being, my ability to work, and my financial independence.”

Theme 5: Children’s vs. Adult Services

The shift from flexible, creative children’s services to rigid adult services was highlighted. This transition represents a missed opportunity to sustain positive approaches and raises concerns about the continuity of rights as people age. It also undermines independence and control at key life stages.

“In children’s services, there was lots of flexibility for option 1 to use for outcomes, but adult services it's about hours of support, which is like old direct payment ways.”

When asked about being able to use the budget flexibly, one participant said,

“Not in adult services but absolutely in children’s services.”

However, challenges faced within children's services were also highlighted for families:

QUESTION 2
(CONTINUED)

"There are no service providers that work with children locally, so it means we have to just take the local authority provision, as there is no choice, so therefore no control."

"My son was awarded £11.5k, but despite doing the required training with GCIL and repeatedly asking for the card needed to manage the money, I was never given it. I was told £3,000 was taken off because it "wasn't used," even though I have emails proving I was actively requesting access. Other parents online seem to have choice and flexibility, but I've been blocked completely."

Concluding thoughts

The Self-Directed Support (Scotland) Act 2013 and the SDS National Improvement Plan 2023-2027 commit to the principles of:

- **Participation and dignity** – people should be central to decision-making.
- **Informed choice and control** – individuals should have genuine flexibility to meet personal outcomes.
- **Collaboration and co-production** – professionals and citizens should work together in trust.
- **Equality** – people should have fair access to opportunities, regardless of geography or circumstance.

Feedback has shown us that where flexibility was supported, people reported life-changing benefits that exemplify these principles, demonstrating that SDS can and does work.

However, the widespread experiences of restriction, bureaucracy, and inequality reveal that practice often contradicts policy. Instead of enabling self-direction, rigid systems push people back into service-led models, undermining independence and wellbeing.

QUESTION 2
(CONTINUED)

To realise the vision of SDS, Scotland must:

- Ensure consistency in applying SDS guidance across all local authorities.
- Remove bureaucratic barriers and create trust-based, outcome-focused systems.
- Protect and extend flexibility into adulthood, particularly at key transitions.
- Treat lived experience as equal expertise in shaping how budgets can be used.

Only by embedding these changes can SDS deliver on its promise:
to give people genuine choice, control, dignity, and independence
in their lives.

QUESTION 3

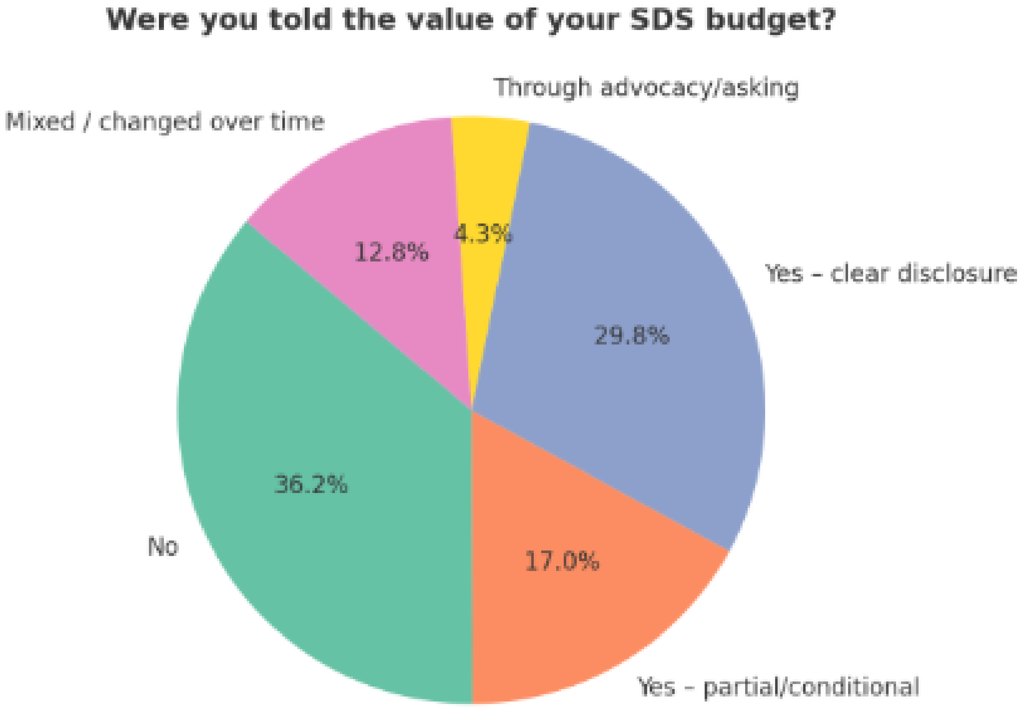
3.3 Were you told the value of your budget?

Experiences of whether people are told the value of their SDS budget are inconsistent across Scotland. Some individuals receive clear, transparent information early in the process, while others are never informed or only discover their budget through persistence or third-party routes. For many, this lack of clarity fosters confusion, disempowerment, and mistrust of the system.

The evidence we gathered points to significant cultural and procedural variation across local authorities, with transparency often dependent on individual practitioners or whether someone is using SDS Option 1, 2, 3, or 4.

These inconsistencies go against Standard 12 of the SDS Framework of Standards, which details the transparency that should be present in allocating budgets.

Statistical breakdown in relation to Q3:



- No (not told the value of their SDS budget): 36.2%
- Yes – clear disclosure: 29.8%
- Yes – partial/conditional disclosure: 17.0%
- Mixed / changed over time: 12.8%
- Through advocacy/asking: 4.3%

QUESTION 3
(CONTINUED)

This shows that over a third of respondents were not told their SDS budget at all, and less than a third received clear, upfront information, with the remainder relying on partial, inconsistent, or advocacy-driven disclosure.

We have gathered the feedback received from online questionnaires and face-to-face conversations that took place and collated it into key themes for learning and reflection.

Key themes identified:

1. Transparency and Access to Budget Information is Inconsistent

The information we gathered painted a varied picture. Some people are told the budget clearly at the assessment stage:

"Yes. At the assessment stage they were very open and transparent. I was told exactly how many hours and the budget value. In fact, I got more than I initially asked for."

Others only discover their budget after funds appear in their account, or not at all:

"Social work department just paid into my bank account, with no explanation."

"No, I haven't been informed of the actual value of my budget."

"No Social Work handles it all, we know we have X amount of hours, but not how much the money is."

Some participants shared that they believed their experience demonstrates that Option 1 users (direct payments) are more likely to know, while those on Options 2 and 3 often do not. This inconsistency undermines fairness and equality in how SDS is applied across Scotland.

2. Power Imbalances and Disempowerment

Some respondents describe being deliberately excluded:

QUESTION 3
(CONTINUED)

“I’ve encountered professionals who believe disabled people shouldn’t know their budgets, which reflects a wider cultural issue within some local authorities.”

Not being told creates a sense of power imbalance and exclusion from decision-making:

“Not having this information makes me feel left out of important decisions about my own life.”

“There was limited information provided on what the budget could and could not be spent on”

Whilst a fear of challenging decisions is common:

“I’m always so scared they take it away from me so I’m very careful about what I challenge them on.”

I wasn’t told the value of my budget until I completed a leadership programme called Partners in Policymaking, that gave me the confidence to ask. That was a turning point. Before that, no one had ever discussed the budget with me in monetary terms and I was scared to do.”

This points to systemic issues of trust, dignity, and respect.

3. Timing, Clarity, and Practical Use of Budgets

In some cases, budgets were shared late or without explanation:

“We are on year 4 now and have never heard exactly what budget has been yearly since (the initial assessment) .”

“Yes, but no guidance as to how this can be utilised.”

Feedback from participants also demonstrated people discovering hidden costs (insurance, payroll, overheads) that reduced the real value of their budget:

“She was told a figure but quickly realised costs like insurance had not been factored in.”

QUESTION 3
(CONTINUED)

Whilst a lack of clarity makes it difficult for people to plan effectively, use creativity, or ensure fair value.

4. Budget Rigidity and Pre-determined Allocations

Many participants reported not being involved in how budgets are calculated or used:

"I was told it was £11.5k and I was told after that social work had already decided how it should be used."

For some, this removes the flexibility and personalisation that SDS is designed to enable.

Some participants reported inequities in allocation when local respite services are unavailable:

"Using PAs for overnight respite is far more expensive... but our son's access to local authority respite has been significantly limited."

This highlights a disconnect between the aspirations of SDS policy and the practical challenges of local implementation.

5. Systemic Variability and the "Lottery" of Local Authority Practice

Feedback highlighted a disparity amongst local authorities, with some local authorities open and transparent, while others guard budget information:

"At the start yes, but now the Council keep it a very closely guarded secret!"

Some participants noted reductions after financial assessments, leading to disruption:

"...situations where the financial assessment has been completed some time after the budget has been shared and following this the budget has been reduced which has impacted on the support we were planning."

Overall, people's access to budget knowledge depends too heavily on local practice, creating a "postcode lottery" in SDS implementation.

QUESTION 3
(CONTINUED)

Concluding thoughts

The Self-Directed Support (Scotland) Act 2013 places choice, control, and participation at the heart of social care, yet the evidence shows that lack of transparency around budgets continues to undermine these principles. Too often, people feel excluded, disempowered, or left to navigate hidden costs and pre-determined decisions without clarity or consistency.

To close this gap, Scotland must make budget transparency a universal right, in line with the practice laid out in the SDS Framework of Standards, and backed by accessible written information provided at the outset of support planning.

Local authorities need to apply consistent standards to avoid a postcode lottery, while professionals must be equipped and supported to treat disclosure as a matter of rights rather than discretion. Hidden costs such as insurance and payroll must be addressed openly, and monitoring should focus not only on SDS uptake but also on people's lived experience of control.

Ultimately, fulfilling the vision of SDS requires embedding a culture of trust and respect between social work and citizens, tackling inequalities in delivery, and reaffirming that SDS is not just about managing resources but about enabling rights, empowerment, and meaningful choice in people's lives.

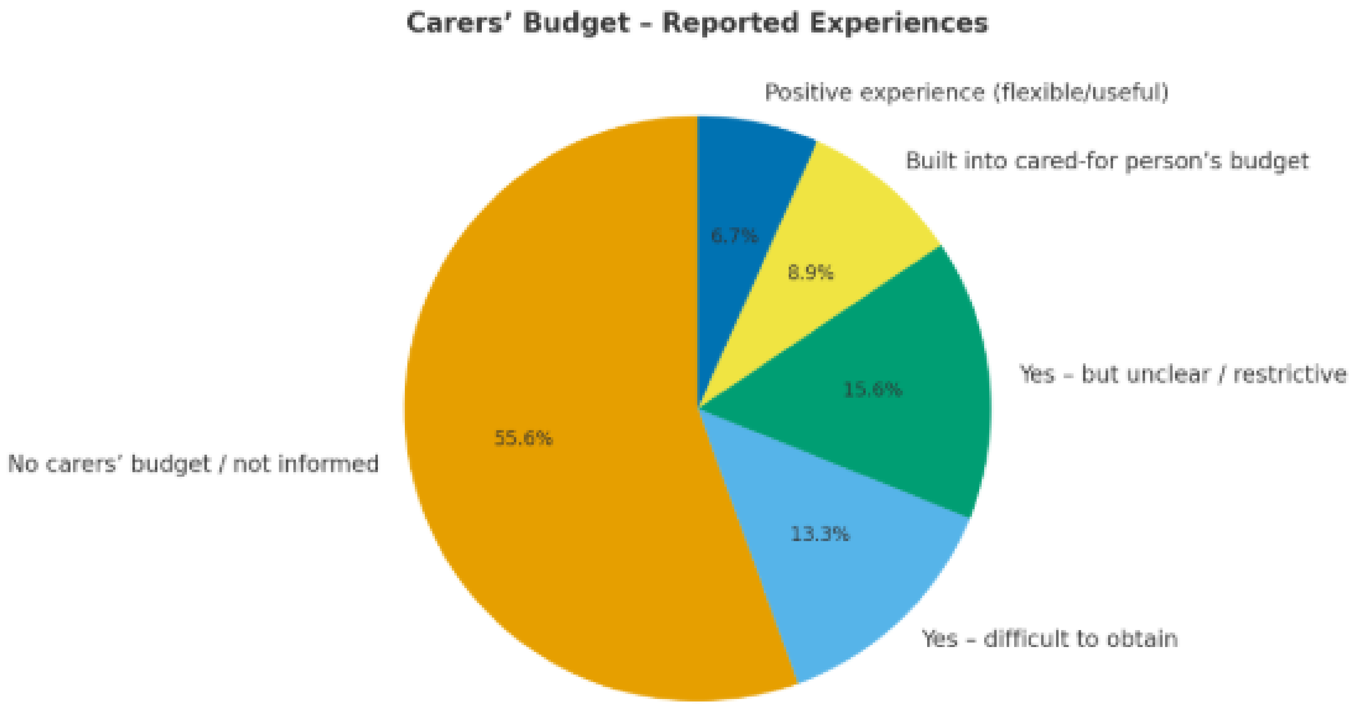
QUESTION 4

Evidence gathered from carers continues to highlight significant inconsistencies and barriers in accessing and using a carers' budget in Scotland. Many carers are unaware of their entitlement, others find the process confusing or adversarial, and even when a budget is granted, it often lacks the flexibility and clarity needed to make a meaningful difference.

Carers report systemic problems: lack of information, restrictive interpretations of legislation, reliance on informal networks to access entitlements, and a deep mismatch between policy aspirations (choice, control, recognition, prevention) and practice reality (gatekeeping, lack of guidance, crisis-driven responses).

This undermines the intent of both the Carers (Scotland) Act 2016, which sought to ensure carers' needs are identified and supported, and the SDS Act 2013, which is the mechanism for organising carer support.

Statistical breakdown in relation to Q4:



- No carers' budget / not informed: 55.6%
- Yes – difficult to obtain: 13.3%
- Yes – but unclear / restrictive: 15.6%
- Built into cared-for person's budget: 8.9%
- Positive experience (flexible/useful): 6.7%

QUESTION 4

(CONTINUED)

We have gathered the feedback received from online questionnaires and face-to-face conversations that took place and collated it into key themes for learning and reflection.

Key themes identified:

1. Lack of Awareness and Information

Many carers are not told they are entitled to a budget, or only discover it through chance or persistence. Information is often poorly communicated or withheld.

“It was the GCIL advisor that told me what I was entitled to, the social worker never mentioned it.”

“No, I don’t know anything about that. No one has ever spoken to us about it and I have been caring for my mum for 4 years now.”

“No, I don’t have a carers’ budget. Despite the huge impact on my life — giving up work, struggling with my own mental health, and having no support while caring for my son — nothing has been offered. Even when I raised how much this situation has affected me, there’s been no recognition or practical support as a carer.”

“No I don't have a carers budget. I have an adult carers support plan in place but no one has ever spoken to me about applying for a budget myself. I’m not even sure i am eligible because I work.”

This reflects a failure to implement the duty under the Carers Act to provide clear information and support planning.

2. Confusing, Rushed, and Adversarial Processes

Where assessments do happen, carers describe them as inconsistent, confusing, and sometimes intimidating.

“The assessment was conducted by a social work assistant who was kind but made errors and seemed rushed.”

“Yes, it was absolutely horrendous to get.”

QUESTION 4
(CONTINUED)

"No. I have been told I am not eligible – no details – just that my needs weren't sufficiently high!"

Carers often feel they must **"fight"** to access support, creating a culture of gatekeeping rather than one of rights and recognition.

3. Restrictions on Flexibility and Misinterpretation of Legislation

Budgets are often tightly controlled, limited to respite, or subject to unclear rules that contradict the flexibility intended in policy.

"I do have a carer's budget – it was easier to get than to spend! I have paid back thousands... because I've been unable to spend my budget (due to unclear guidance on what's 'allowed')."

"I was told I should only spend my carer's budget on residential care for my disabled daughter... the council has interpreted the only critical need as respite."

"Limiting it to Replacement Care is not right. I should be able to use my carers budget flexibly."

This reveals a fundamental misalignment between legislation (which emphasises prevention, wellbeing, and choice) and local authority practice (which narrows support to crisis-driven respite).

4. Reliance on Informal Support and Self-Advocacy

Carers frequently rely on family, peer groups, or voluntary sector organisations to access entitlements, highlighting weak statutory pathways.

"My daughter-in-law helped me to access support. No-one had ever told me there was help available for me and not just my disabled daughter."

"Not initially, it was the GCIL advisor that told me what I was entitled to."

"I think a very small one and it's put in with my respite budget. I don't challenge this... not worth me rocking the boat."

This reliance on informal navigation adds stress and creates inequalities,

QUESTION 4
(CONTINUED)

between those who can self-advocate and those who cannot.

5. Mismatch Between Policy Aspirations and Carers’ Realities

While legislation emphasises recognition, prevention, and rights, carers report exclusion, financial strain, and a lack of meaningful respite.

“Despite the huge impact on my life — giving up work, struggling with my own mental health, and having no support — nothing has been offered.”

“As carers we often feel overlooked and unsupported... sometimes it feels like the system only steps in when things reach a crisis point.”

“The council is only able to meet carer’s needs that meet the critical threshold due to the lack of financial resources.”

This reflects the tension between progressive policy ambitions and the financial/resource constraints shaping practice.

Concluding Thoughts

The experiences shared by carers across Scotland reveal a system that too often falls short of its legislative promises. Despite the progressive intent of the Carers (Scotland) Act 2016 and the SDS Act 2013, carers continue to face barriers that limit their access to support, erode trust, and reinforce inequality. To honour the rights of carers and realise the full potential of self-directed support, urgent action is needed to improve transparency, consistency, and flexibility in how carers’ budgets are communicated, assessed, and delivered.

QUESTION 5

3.5 What do you think needs to change / what would it take to close the gap between your experience and living a good life?

We know that Scotland's Self-Directed Support (SDS) legislation was designed to empower disabled people and their carers, giving them choice, control, and autonomy over their support. In practice, the feedback we have gathered from disabled adults and carers reveals a system that too often falls short of this vision. Rigid budgets, confusing processes, bureaucratic delays, and a lack of genuine involvement leave many disempowered, exhausted, and isolated.

We asked people what they think needs to change or what would it take to close the gap between their experience and living a good life and six key themes emerged: Empowerment & Voice, Flexibility & Control over Budgets, Transparency & Communication, Carer Identity & Wellbeing, Systemic & Workforce Challenges, and Accessibility, Social Connection & Belonging.

Across all these areas, there is a recurring tension between the vision of SDS: person-centred, empowering, flexible and the reality on the ground. This learning report presents the evidence we have gathered from lived and loved experience, highlighting the gap between vision and reality.

We have gathered the feedback received from online questionnaires and face-to-face conversations that took place and collated it into key themes for learning and reflection.

Key themes identified:

1. Empowerment, Voice & Participation

At the heart of SDS is the principle that people should control the decisions that shape their lives. Yet, many report feeling sidelined and unheard. Disabled people and carers emphasised the need for their voices to be genuinely heard and for decision-making processes to be inclusive.

QUESTION 5
(CONTINUED)

One participant explained, *“More people need to have a voice… giving this information and feedback shouldn’t feel like a fight; it should be a positive and supportive process.”*

Others echo this sentiment, calling for the involvement of *“normal people, who are living a life with support, in decision-making processes.”*

Trust is a central issue. Many participants expressed a desire for autonomy over their budgets, free from constant oversight or repeated reassessments: *“Ideally, I’d like to see a shift where people are trusted to use their budgets as they see fit, without needing constant permission or going through panels.”*

Disabled adults and carers want decision-makers to experience life on the ground, as one person stated, *“People at the top should go out with social workers and find out what it’s really like for disabled people and families trying to survive.”*

The evidence gathered, highlights a systemic failure to embed genuine co-production in SDS. Where consultation exists, it is often tokenistic, leaving individuals feeling invisible and powerless. There is a pressing need for a cultural shift in how authorities engage with lived experience, moving from compliance to collaboration.

2. Flexibility & Control over Budgets and Support

SDS is intended to be self-directed, yet participants describe budgets that are restricted, inflexible, and narrowly focused on hours of care. *“The SDS budget should not be so restricted; greater flexibility is needed,”* one person said.

Many emphasised that support should focus on outcomes rather than a rigid allocation of hours: *“Flexibility to meet outcomes rather than constant reference to support hours.”*

Participants shared that they want the ability to use their budgets to pursue social, recreational, and personal goals. One described how most budgets *“Do not include time or money to socialise or be part of a community or feel a sense of belonging,”* highlighting the gap between survival-focused care needs and support for a meaningful life.

QUESTION 5
(CONTINUED)

Others described the stress of being forced into roles they did not want, such as employing personal assistants without adequate support: ***"I never wanted to become an employer, but there is no building-based support… it was option 1 or nothing."***

Practical barriers, such as complicated procedures and fear of ***"misspending,"*** compound these challenges: ***"Easier support, cut out the jargon and make it easy and simple to follow and hide nothing from people receiving care and support."*** This evidence underscores that true self-directed support requires flexibility, trust, and a focus on outcomes rather than rigid rules.

3. Transparency, Communication & Accountability

From the feedback gathered from participants, they report poor communication and unclear decision-making as major obstacles to effective SDS.

Many experience frustration with delays, jargon, and inconsistent guidance. One participant said, ***"It just took over 6 months to do my daughter's review… communication with Social Work is awful… too many delays."*** Others emphasised the need for transparency in budget management: ***"A monthly statement showing the makeup of the payment credited to the account… written guidance as to how the payments can be used with/without pre-authorisation."***

Lack of accountability erodes trust: ***"Complaints shouldn't just be dismissed, and budgets shouldn't be withheld without explanation."*** There is a strong call for authorities to be open, honest, and timely in their communications, providing clear pathways for complaints, guidance, and feedback. When information is inaccessible or delayed, service users are forced to navigate complex systems alone, creating stress and undermining the promise of empowerment central to SDS.

4. Carer Identity, Wellbeing & Respite

Carers are critical to the sustainability of SDS, yet many describe being overstretched, undervalued, and unsupported. ***"We have no personal time as a carer… I want to be seen as a person, not just a 'service user,' "*** explained one respondent.

QUESTION 5
(CONTINUED)

Others report a lifetime of caring responsibilities leading to *"personal loss of identity and aspirations."*

The need for meaningful respite and dedicated carer support is clear. One parent described the struggle to access breaks: ***"For me as a carer, I need better support to get regular, meaningful time for myself, without having to fight or bend rules to make it happen."***

Workforce issues also impact carers, including the availability of trained personal assistants: *"Finding more great PAs who can drive in order to support my child and give me greater opportunities for respite... improvements in wages and training for support staff."*

The cumulative impact on carers' mental health, employment, and personal life is profound, illustrating that SDS cannot succeed without recognising carers as equal partners and supporting their wellbeing.

5. Systemic, Cultural & Workforce Challenges

Many participants highlight bureaucracy, systems, and workforce shortages as fundamental barriers to effective support. *"Systems need to be modernised—faster, more streamlined, and transparent,"* one person stated.

Social workers are sometimes perceived as insufficiently trained or unable to advocate: ***"Social workers need to return to the values they were trained with and advocate for the people they support."***

Recruitment and retention of care staff are recurring challenges: *"Big issue is recruitment of care staff—it needs to be tackled meaningfully. Needs a change of culture within local authorities"* Legal empowerment is also necessary to ensure accountability: *"Legal aid so people can make Local Authorities follow the law."*

Addressing these challenges requires cultural as well as structural reform, shifting from a risk-averse, control-driven system to one based on trust, empowerment, and advocacy.

QUESTION 5

(CONTINUED)

6. Accessibility, Social Connection & Belonging

SDS should extend beyond basic care to support social participation, inclusion, and emotional wellbeing. Yet participants report that budgets and services often fail to address these aspects of life: ***“Support should be about helping me live a full life, not just about managing risks or ticking boxes.”***

Social and recreational activities, transport, and community engagement are frequently underfunded: ***“A separate budget for transport is essential, especially for those who are transport-dependent.”***

Geographic isolation and rural contexts exacerbate inequities: ***“Limited access to carer centres and support networks… the rural context exacerbates feelings of being forgotten and unsupported.”*** Without support for social connection and belonging, SDS risks enabling survival rather than independent, fulfilling lives.

Concluding Thoughts

The lived and loved experience we have gathered shows that SDS is still a system in transition, caught between legislative ambition and bureaucratic reality.

For people to truly live the lives the legislation envisages, Scotland must rebuild trust, simplify processes, empower carers, and enable social participation. Without systemic reform, SDS risks remaining a hollow promise—empowerment in law, but constraint in practice. We need to listen to the feedback that has been gathered and implement real change in Scotland.

CONCLUSION

Scotland's Self-Directed Support (SDS) legislation was designed to empower disabled people and their carers, offering genuine choice, control, and flexibility over support. It envisions a system where services are shaped ***with*** people, not merely delivered ***for*** them, promoting independence, wellbeing, and meaningful participation in social care planning and support.

The evidence gathered through Connected Conversations highlights that, while pockets of positive practice exist, the reality experienced by most participants falls far short of this vision.

Positive engagement, when well supported, builds confidence, skills, networks, and leads to tangible improvements in services. However, many people report tokenistic consultation, restricted budgets, bureaucratic hurdles, and exclusion from decision-making processes. Carers often feel undervalued, overburdened, and unsupported, while systemic barriers such as workforce shortages, rural isolation, and inconsistent local authority practices reinforce inequalities.
The gap between vision and reality is stark.

SDS promises empowerment, flexibility, co-production, and equality, yet in practice:

- **Disempowerment** is widespread, people frequently have to fight to be heard or to access support.
- **Inflexible budgets** limit choice and creativity, often prioritising traditional service models over individual outcomes.
- **Lack of transparency** erodes trust, with confusing processes, delayed communication, and inconsistent guidance.
- **Carers remain undervalued**, with insufficient support for wellbeing, respite, and personal development.
- **Systemic gaps hinder delivery**, including workforce shortages, outdated systems, and uneven implementation across local authorities.

This evidence underscores that Scotland's SDS system is still a work in progress. Transforming it into the rights-based, person-led system envisaged by legislation will require sustained cultural, structural, and procedural reform. Key priorities include:

- Rebuilding trust and accountability through transparency, clear communication, and timely follow-up.
- Increasing flexibility and control over budgets to support outcomes, social participation, and independent living.

CONCLUSION
(CONTINUED)

- Recognising and supporting carers as equal partners with access to respite, resources, and wellbeing support.
- Embedding genuine co-production, ensuring lived experience informs planning, policy, and decision-making at all levels.
- Addressing systemic barriers, including workforce shortages, bureaucracy, and geographic inequalities, to ensure consistent access and fairness across Scotland.

Only by closing the gap between policy ambition and lived and loved experience can SDS deliver on its promise: a system where disabled people and carers are empowered, supported, and enabled to live full, independent, and meaningful lives. Scotland has the legislation, and the examples of good practice show it is possible—now it requires the courage, investment, and commitment to make it real for everyone.

We would like to thank everyone that took the time to participate in this conversation

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